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ADVANCE DIRECTIVES FOR END-OF-LIFE CARE IN THE ELDERLY – EFFECTIVENESS OF DELIVERY MODES

Bing Guo, Christa Harstall

August 2004

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CONFLICT OF INTEREST

Conflict of interest is considered to be financial interest, either direct or indirect, that would be affected by the research contained in this report, or creation of a situation where an author's judgement could be unduly influenced by a secondary interest such as personal advancement.

Based on the statement above, no conflict of interest exists with the authors of this report.

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EXECUTIVE SUMMARY

Background

End-of-life care decisions for the elderly have become increasingly important because of an aging population. An advance directive (AD) has been endorsed as a means for individuals to guide care before a possible future period of decision incapacity. Although the benefits of ADs have been widely recognized, only about 10% of Canadians have a written AD. The optimal methods to initiate a discussion about an AD and increase the completion rate are the issues addressed in the report.

Objectives

1) To examine the research evidence on the effectiveness of different methods for the delivery and completion of ADs;

2) To seek information regarding the local use of ADs in Alberta.

Results

One systematic review and ten randomized controlled trials (RCTs) met the inclusion criteria. The types of interventions used in the RCTs included provision of written educational materials alone (one RCT), provision of written material plus an educational videotape (three RCTs), provision of written materials plus an interactive seminar (one RCT), an education session plus telephone reminder (one RCT), physician-initiated discussion (three RCTs), and a comprehensive nurse-initiated education program (one RCT).

Limited research evidence indicated that the mailing of written materials about ADs alone could increase completion rates by 18%. Compared to provision of written materials alone, the addition of educational videotapes did not increase completion rate, while the addition of an interactive seminar significantly increased the AD completion rate by 38%. Education session plus telephone reminder did not increase AD completion rates when compared to education session alone. Physicians' discussions with outpatients increased AD completion rates by 15% to 16%. The most comprehensive and complex education program, Let Me Decide (LMD) program, increased AD completion rates by at least 45%. However, in this study AD completion rates included both competent nursing home residents and family members of incompetent residents.

There are many different formats of ADs currently available in Canada as there is no federal law on advance health care planning. Several provinces, including Alberta, have their own legislation.

The Personal Directive Act in Alberta does not require health care professionals to enquire about personal directions nor is there a provincial policy. The Capital Health Authority completed an evaluation study on the LMD Personal Directive Program in 2002 and encountered some difficulties in implementing the LMD program that originated from Ontario.

Conclusions and Recommendations

The optimal method to increase discussions with older persons about end-of-life health care issues and the completion of written directives depends upon various factors such as setting, target population, and the availability of resources.

Provision of written materials in addition to an interactive seminar appeared to significantly increased AD completion rates compared to provision of written materials only. A comprehensive and time intensive education program that included both competent elderly persons and family members of incompetent persons increased AD completion rate by at least 45% but the results can not be compared to other studies due to the difference in study design and reporting.

The best-qualified professionals to deliver AD programs may be determined by the methods used for delivery, the complexity of the ADs, settings, and target populations.

The Personal Directive Act in Alberta does not require health care professionals to enquire about personal directions nor is there a provincial policy. Hence Regional Health Authorities may choose to implement customized programs. Implementing a provincial directive program that is well established in one province needs to take into account the differences in the provincial legislations.

Methodology

Systematic reviews and RCTs were identified by systematically searching PubMed, EMBASE, HealthStar, The Cochrane Library, Science Citation Index, the web sites of various health technology assessment agencies, and guidelines sites from 1993 to 2004. Searches were limited to populations aged 55 years or older.

Reference

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ABBREVIATIONS

AD – advance directive

ANH – artificial nutrition and hydration

CG – control group

CPR – cardiopulmonary resuscitation

DNR – do not resuscitation

DPAHC – durable power of attorney for health care

EG – experimental group

HMO – health maintenance organization

HP – health promotion

LMD – Let Me Decide

min – minute

MMSE – Mini-Mental State Examination

nss – not statistically significant

PD – personal directive

PSDA – Patient Self Determination Act

RCT – randomized controlled trial

SMMSE – Standardized Mini-Mental State Examination

vs. – versus

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INTRODUCTION

This information paper was prepared in response to a request from the Chinook Health Region, Alberta about the published scientific evidence on the effective mechanisms for improving the quality of discussions around end-of-life issues with seniors, especially those residing in long-term care facilities with chronic conditions or diseases. There was a special interest in who should deliver the message and which methods are effective in delivering the program.

Aging population

Today, Canada faces significant aging of its population as the proportion of seniors increases more rapidly than all other age groups [1]. In 2001, it was estimated that one Canadian in eight was aged 65 years or over. By 2026, nearly one in five Canadians is expected to reach the age of 65 years [1].

In Alberta, 9.8% of its population is over 65 years of age [2]. This number is expected to increase to 14.5% by 2016, and by 2031, approximately one in four Albertans will be over the age of 65 years [2]. In Alberta, approximately 4.2% of seniors resided at 157 long-term care facilities in 1999 [3].

In the United States, more than 2 million deaths occur each year, with more than two-thirds of them occurring among persons aged 65 years or older [4]. In contrast to the traditional way of dying at home, health care institutions, especially long-term health care facilities such as nursing homes, have increasingly become the site of death for the elderly [5]. Approximately 1.5 million Americans resided in 16,700 nursing homes in 1995 [6]. Of all deaths in the United States in 1993, 20% occurred in nursing homes, and the proportion of deaths occurring in nursing homes is expected to increase to 40% by 2020 [7].

End-of-life health care for the elderly

End-of-life care decisions have become increasingly important because of an aging population, rapidly escalating health care costs, new life sustaining technology, increasing patient awareness and demands for autonomy, and increasing litigation associated with health care [8].

Patients and their families have become more involved in the treatment decision processes in recent years. However, as many as 75% of American patients lack decision-making capacity when they have to make choices about life-sustaining treatments [9]. Decisions on end-of-life medical care are usually made after patients have lost decisional capacity because of acute illness or progressive dementia [10].

There is a perception that complex technologies are used inappropriately in the last few weeks of a person's life. For example, in the United States, 5% to 6% of elders who die each year incur 28% to 30% of that year's Medicare expenditures [11]. In Canada, health expenditures for seniors aged 85 years or older were four times that of seniors aged 65 to 74 years in 2000 to 2001 [2].

A number of interventions have been studied to address the problems in end-of-life care, including education of patients and physicians, written advance directives (ADs), and facilitated discussions with documentation of treatment choices on the medical record [12]. These interventions are aimed to meet clinical goals, taking account of patient treatment preferences, minimizing pain and suffering, reducing inappropriate use of life-sustaining treatments, and reducing costs [12].

ADs are a mechanism by which competent persons plan for medical decision-making at some future time when they might have lost their decision-making capacity. In other words, ADs are ***directions*** to others about health care issued ***in advance*** of end-of-life care [13].

The key, policy-relevant hypothesis behind ADs proposes that if an intervention enhances a person's right to choose, then that person will not opt for technological and costly medical care, that physicians will honor that choice, that alternative palliative care will be less costly, and that an ethically defensible saving of resources will result [7]. Three steps - the completion of an AD, physician's recognition of ADs, and physician's honoring of person's choice for medical care - are of critical importance. This report focuses on the first step and searches for effective methods to enhance the completion of ADs by elderly persons.

OBJECTIVES AND SCOPE

The objective of this report is to examine the research evidence on the effectiveness of different methods for delivering ADs to the elderly (defined as age ≥55 years), particularly those who have chronic conditions or terminal diseases and reside at long-term care facilities such as nursing homes or in communities. In this report, the term ***"delivery mode"*** is defined as any method, such as mailing out materials, physician-patient discussions, education programs, interactive seminars, or videotapes, that was used to improve the knowledge about ADs and increase completion of ADs and/or discussions between patients and physicians or family members about ADs.

This report also provides some information regarding the use of ADs within regional health authorities in Alberta.

The effectiveness of interventions for delivering ADs to younger persons or to acutely, critically ill patients in hospitals, emergency departments, or intensive care units will not be addressed in this report. Cost-effectiveness of the use of ADs will be assessed in another report.

ADVANCE DIRECTIVES

Definition

An AD is a written document in which a competent person sets out health care preferences before incapacity occurs [14]. It may be used to specify instructions for care, or name a surrogate decision maker, or both [14].

In ethical theory, the primary goal of advance health care planning is to assert a person's autonomy and preferences before they become unable to make decisions at a future time [13]. Such advanced health care planning will help elderly persons to express their wishes, extend autonomy, and guide their families and health care workers to provide care consistent with their choices [15]. ADs are particularly relevant for the increasing number of the elderly who may be able to confront their death with less anxiety if they feel assured that technological interventions will not prolong the dying process unnecessarily [16].

The majority of ADs have been used to instruct health care professionals to initiate, continue, withhold, or withdraw medical treatments such as mechanical ventilation, cardiopulmonary resuscitation (CPR), dialysis, antibiotics, surgery, invasive diagnostic procedures, or artificial nutrition and hydration (ANH) [17].

Types and forms

ADs can be divided into two categories: instructional and proxy directives [18, 19].

Instructional directives allow a person to identify what or how health care decisions are to be made if they become incompetent [18]. Instructional directives are at times referred to as living wills, end-of-life instructions, or treatment directives [17].

Proxy directives allow a person to nominate or specify who is to make health care decisions in the event that they become incompetent [18]. Proxy directives are at times referred to as power of attorney for health care, mandate for health care, appointment directives, substitute decision maker for health care, or personal directive agent [17].

The two most frequently recorded types of ADs are the living will and the durable power of attorney for health care (DPAHC) [20-22]. The living will and DPAHC are the two legal and formal mechanisms for documenting ADs [23]. The living will describes a person's specific instructions about their desire to have or not to have certain life sustaining procedures administrated when they are permanently incapacitated or unable to voice their preferences [23]. The DPAHC, sometimes called the ***"health care proxy"***, allows the authorization of someone else to make health care decisions on a person's behalf should they become terminally ill or incapable of communicating whether or not they wish to be placed on life support [23, 24]. A more comprehensive type of AD combines the living will with the designation of a proxy [20].

According to the Canadian Association of Critical Care Nurses [17], many different formats of ADs are currently available in Canada. A combined document of a living will and DPAHC has been suggested to provide the best assurance for respecting persons' desires for critical medical care. One such example is the ***Let Me Decide Health and Personal Care Directive***, which was developed by Molloy and has been used in Ontario nursing homes [25].

The Let Me Decide (LMD) Health and Personal Care Directive is a comprehensive and complex document consisting of instructional and proxy components, providing a range of health care choices for life-threatening illness, cardiac arrest, and feeding [15]. The directive contains four parts:

1) an introduction stating the person's reasons for completing the directives;
2) a personal health care chart;
3) definitions and terms used in the personal care chart; and
4) a personal statement where each person describes what they consider an irreversible condition [26].

In this document, four treatment options, including supportive care or palliative care, limited care, surgical care, and intensive care are offered in the event of life-threatening illness. The document also allows persons to express their wishes for CPR and feeding options.

Interventions to deliver ADs and rates of AD completion

Three levels of intervention to deliver an AD are outlined in the literature [27]:

- **Minimal intervention**, such as distribution of a pamphlet, usually achieves a 5% to 15% completion rate.
- **Simple education** combines provision of pamphlets with a short face-to-face explanatory interaction, usually resulting in a 15% to 25% completion rate.
- **Complex intervention** like the LMD, where the professional spends 50 to 90 minutes with each person spread over two or more visits, results in a 50% to 80% completion rate.

Despite the benefits of ADs and the fact that many people like the idea of ADs, few people actually complete them [10]. The average rate of AD completion in Canada is approximately 10% [28]. About 2% to 15% of Americans have an AD document [29]. The majority of Americans do not have written ADs and health institutions rarely collect information about directives even when they are completed [5].

Although there are many barriers for not completing ADs, the most cited reasons are the lack of knowledge about ADs and understanding of life-sustaining treatments and outcomes, and mistrust of ADs as effective means to exert control over future care [27, 30]. The optimal method to increase discussions with patients about end-of-life issues and the completion of written directives remains unclear [31]. Many institutions and clinicians are struggling to find effective ways of communicating information to persons about ADs [30].

Legislation

Canada

In Canada there is no federal law on advance health care planning that would be similar to the Patient Self-Determination Act in the United States [16]. Provinces such as Ontario, Prince Edward Island, Saskatchewan, Alberta, and British Columbia have more or less relevant legislations in this area (Bob Mitchell, personal communication, Feb 2004):

- Ontario – Substitute Decisions Act;
- Prince Edward Island – Consent to Treatment and Health Care Directives Act;
- Saskatchewan – Adult Guardianship and Co-Decision Making Act, and Health Care Directives and Substitute Health Care Decision Makers Act;
- Alberta – Personal Directive Act; and
- British Columbia – Representation Agreement Act.

The Personal Directive Act became law in Alberta in December 1997. The Personal Directive Act was developed for all Albertans over 18 years of age, but seniors appear to have shown the greatest interest. A personal directive (PD) is a legal document that covers broader aspects of personal matters than ADs that only focus on issues regarding health and medical treatments. Although PDs also typically address health and medical treatment decisions, a PD may be less effective in situations of a critical medical incident. The wishes of the person expressed in the directive can only be followed after the standardized Declaration of Incapacity form has been completed.

The United States

In the last 15 years, there has been a growing movement to encourage people to provide instructions regarding decisions about life-sustaining treatment in advance of critical illness and the loss of decision-making capacity [32]. In December 1991, the Patient Self Determination Act (PSDA) became a federal law [33, 34]. This is a national ongoing effort to address one potential barrier to the use of ADs, access to information [30]. The PSDA requires all hospitals, nursing homes, and health care agencies to inform patients about their right to accept or refuse medical treatment, and to execute an AD [16, 35]. However, primary care physicians are not required to ask every new or elderly patient if he or she has executed an AD or is interested in doing so [36]. Each State now has advance directive legislation [16].

EVIDENCE ON THE EFFECTIVENESS OF VARIOUS AD DELIVERY INTERVENTIONS

One systematic review [12] was found that assessed research evidence on the effectiveness of interventions in increasing the use of personal preference by completing ADs. This review was published in 1997 and included studies with different designs such as randomized controls or historical comparisons.

Ten randomized controlled trials (RCTs) [9, 15, 28, 30, 31, 37-41] met our inclusion criteria and were selected for analysis (see Appendix A). Only one of these RCTs [9] was included in the systematic review mentioned above [12].

Two studies [15, 28] were conducted in Canada, while eight studies [9, 30, 31, 37-41] were conducted in the United States. AD programs were either delivered to nursing home residents [15, 30], senior outpatients [9, 31, 37-41], or seniors who attended a senior centre [28].

Details about intervention, participant, setting and delivery, and outcome from the RCTs are summarized in tables in Appendix B.

Evidence from systematic reviews

The systematic review [12] examined the relation between the type of intervention and its success in achieving four clinical goals:

1) increasing the use of personal preference,
2) minimizing pain and suffering,
3) reducing the use of life-sustaining treatments, and
4) reducing costs.

This review included 16 studies that had various designs (e.g., RCTs, historical comparison, or no control group) and measured AD completion rates. Studies that only measured changes in attitudes or knowledge were not included in this review. The ages of the participants in the included studies were 18 years or older. Only information regarding the AD completion among the elderly from outpatient settings or long-term care facilities is presented here.

Interventions that targeted patients included discussions with researchers or social workers, written materials, and educational meeting. All interventions provided patients with education about life-sustaining treatments and their right to express preferences about the use of these treatments. Baseline rates of documented preferences or proxies ranged from 0% to 31% and rates of recorded ADs after the interventions ranged from 15% to 71%. The most successful interventions did not rely on written materials alone. More people recorded preferences when they had repeated opportunities to discuss their decisions with a social worker.

Interventions that targeted physicians included expert modeling, extra clinic time, and physician lecture chart reminder. None of the studies used randomly assigned controls. Two interventions attempted to increase the use of patient preferences by increasing the number of written ADs in outpatient records. The researchers found that didactic education alone was not sufficient to change physician behaviour. A high success rate was achieved when patients and physicians had repeated opportunities for discussion before completing written ADs.

Interventions that targeted both patients and physicians included patient and family education, and physician education. Participants in these studies were those who were at increased risk for death because of severe life-limiting chronic illnesses or advanced age and functional impairment. All these interventions increased the completion and recording of ADs but failed to show a difference in use of life-sustaining treatments or other outcomes of interest such as survival, health status, or patient satisfaction.

The authors of this review found that the extent of success of interventions in AD completion varied with patients' characteristics and the educational techniques used. Healthier patients, similar to the general population, are willing to complete an AD about 15% of the time. For outpatients, higher rates of AD completion were achieved by written materials combined with repeated clinical discussions. Most severely ill patients are willing to complete an AD. Discussions can be initiated by a physician but are also effective when conducted by a social worker or patient advocate. Physicians may require extra clinic time, chart reminders, convenient forms, or peer modeling and feedback if they are expected to initiate such discussions.

Evidence from RCTs

The evidence from the RCTs is presented according to the outcomes measured: changes in AD completion and discussion rates and changes in knowledge and comprehension. These studies are further categorized according to the types of interventions evaluated.

Studies that measured AD completion/discussion rate

Seven studies [9, 15, 28, 31, 37-39] measured rates of AD completion and/or discussion about ADs after the intervention.

Provision of written materials only

Rubin et al. [9] examined the effect of a simple educational intervention on increasing the completion rate of the DPAHC. One thousand one hundred and one patients recently discharged from an acute care hospital were randomly assigned to the intervention group (mailed educational materials about DPAHC) or the control group (conventional care where discussions about DPAHC were at the discretion of the physician and patient). Telephone access for assistance and additional information was also available for the intervention group. The educational pamphlet was tailored for an elderly population and used a question-and-answer format and several thought-provoking case vignettes. Competent patients (method to assess patients' competency was not reported) completed DPAHCs.

Baseline characteristics (age, gender, ethnicity, marital status, utilization of health care services in the year prior to the intervention, and principal diagnosis) were comparable in the two groups. The completion rate of the DPAHC form was statistically significantly increased in the intervention group when compared to the completion rate in the control group after five months.

The authors noted that there were similar proportions of females and males and unmarried and married persons who completed the DPAHCs. Blacks and Hispanics, on the other hand, were significantly less likely to complete DPAHCs than non-Hispanic Caucasians and Asians.

Only 28% of patients in the intervention group specified health care preferences on the DPAHC forms. Of these, 90% of patients wanted only some life-sustaining interventions, while 3% wanted all medical treatment available.

As the authors pointed out, recent hospitalization may make this group of patients more receptive to ADs. It is possible that thinking about end-of-life health care issues at home with printed materials is more comfortable for patients than face-to-face discussions with physicians.

Provision of written materials and videotapes

Brown et al. [37] compared the effectiveness of the mailing of written materials only and the mailing of a videotape along with written materials. Outcomes of interest included a change in the completion and placement of ADs on the medical records by seniors who used health care services provided by a not-for-profit group-model health maintenance organization. The primary objective of the videotape was to increase participants' motivation to complete a directive by exposing them to the personal experiences of others. Randomization yielded two groups that were similar in terms of mean age, gender distribution, and proportion of individuals who had completed an AD prior to the intervention. The two groups had almost an identical increase in the placement of ADs on their medical records at the end of three months.

It was not clear why videotape exposure did not result in an additional increase in AD placement on the medical record. According to the authors, it may be that videotapes have limited impact on an older population that is not video-oriented. Another reason may be that knowledge is not the rate-limiting factor in AD completion among the elderly. The availability of a nurse to answer questions and receive and place ADs on the medical records may have contributed substantially to the success in both groups. Inclusion of the videotape with written materials may be appropriate to enable seniors to make better-informed decisions about ADs, but not merely to increase completion rates.

Provision of written materials and interactive seminar

Landry et al. [31] examined the effectiveness of an educational seminar in addition to providing written information for increasing completion and discussion of ADs among seniors who received care in an outpatient clinic. None of the participants had previously completed an AD. Two groups were similar in terms of age, gender distribution, marital status, ethnic origin, education, health status, and previous discussions regarding end-of-life issues. Seniors in the intervention group were slightly less likely to have had previous knowledge of ADs. The study demonstrated that mailed information alone could increase completion of ADs, including living wills, DPAHC, and organ donation cards. In addition to the written materials, a simple, educational seminar could further increase these completion rates. Seniors most likely to complete the documents were Caucasians, married, or attendees at the educational seminar.

According to the authors, the discussion groups may have allowed seniors the opportunity to ask more questions, receive more answers, and share experiences that otherwise would not have occurred. This intervention may be less time intensive and produce more written documents than one-to-one physician-patient counseling.

Education session and telephone reminder

Hamel et al. [28] examined the effect of an individualized intervention (telephone reminder) in increasing completion and discussion of ADs. Seventy-four seniors were randomly assigned to the intervention group (an education session plus telephone reminder) or the control group (an education session only). Participants were asked to rate their health status using a single–item question.

There were no significant differences between the two groups in gender, age, marital status, occupational group, satisfaction with income, and educational level. The study found no significant difference between the two groups in completion and discussion of ADs. No significant relationships were found between completion and discussion of ADs and the demographic variables such as age, gender, marital status, educational level, and satisfaction with income. Furthermore, no significant relationships were found between completion and discussion of ADs and the independent variables of self-rated health, perceived control, social support, and perceived benefits of ADs. There was a significant inverse relationship between perceived barriers to ADs (a present orientation of life, a tendency toward procrastination, and reluctance to think about one's own death) and completion and discussion of ADs.

Physician-initiated discussion

Dexter et al. [38] examined the effects of computer-generated reminders to physicians on discussion of ADs and completion of ADs. Two types of ADs, instructional and proxy directives, were used in this study. One thousand and nine outpatients and 147 physicians participated and were randomly assigned to one of four groups:

1) instructional directive reminders,
2) proxy directive reminders,
3) instructional directive and proxy directive reminders, and
4) no reminders (control).

Ethnic origin, having cardiac ischemia, and having previous thoughts about ADs differed significantly among the four study groups. The study showed that patients in all three intervention groups reported more AD discussions than did patients in the control group. Patients whose physicians received reminders for both types of directives completed substantially more AD forms than did those patients in the control group and patients whose physicians received only proxy directive reminders. The direct effect of reminders was evidenced by the fact that physicians who received reminders not only had more discussions but initiated them more frequently than did physicians in the control group.

According to the authors, the key was that the intervention was delivered during regularly scheduled primary care visits, when patients were usually not acutely ill and were visiting a physician whom they knew and probably trusted.

Grimaldo et al. [39] evaluated the feasibility of a short (5 to 10 minutes) discussion facilitated by anesthesiologists to increase communication between patients who were scheduled for elective surgery and their proxies. Unlike other studies, this study examined advance care planning discussion by physicians that are not part of the patient's primary care team. DPAHC was used in this study. Two hundred patients were randomly assigned to either the intervention group (a short advance care planning discussion during the pre-operative evaluation) or the control group (usual pre-operative visit).

Baseline demographic characteristics of patients, including age, gender, ethnic origin, education, and physical and mental status, were similar in both groups. The majority of elderly, pre-operative patients have specific wishes about the types of medical treatment that they want but they did not have discussions with their primary care physicians, their surgeons, or their proxies to express their wishes. They understand that a living will or DPAHC can be useful but they never completed one. The study found that the intervention led to a significant increase in AD completion and discussions regarding ADs between patients and their proxies. According to the authors, knowledge about ADs and treatment preferences becomes crucial when peri-operative outcome is not optimal and when prolonged life support is required post-operatively. The anesthesia pre-operative evaluation can be another opportunity to encourage patient and proxy communication about end-of-life care.

Comprehensive nurse-initiated education program

Molloy et al. [15] examined the effect of a systematic implementation of an AD program by measuring the patient's and family's satisfaction with health care and health care service utilization over an 18-month period. One thousand two hundred and ninety-two residents from six Ontario nursing homes were randomly assigned to the intervention (LMD program) and control group (conventional use of ADs). Nurses' experience with residents in other areas of decision making and the Standardized Mini-Mental State Examination (SMMSE) were used to classify the status of residents' competency. Competent residents were educated about the LMD health care directive. For incompetent residents, their proxies completed LMD directives on their behalf.

There were 228 competent residents (36%) and 408 incompetent residents (64%) in the intervention group, compared to 267 competent residents (41%) and 389 incompetent residents (59%) in the control group. The percentage of male residents was higher in the intervention group. At a follow-up of 18 months, 70% of residents (49% competent residents and 78% of families of incompetent residents) in the intervention group had an AD, compared to 57% of the control home residents (the baseline AD completion rates, the percentages of competent and incompetent residents in the control group who completed ADs, and the statistical significance of the difference between the two groups were not reported). Eighty-nine percent of the completed directives in the intervention group were LMD, while 71% of the completed directives in the control group were DNR. No one completed the LMD directives in the control group. This study confirmed that, given the opportunity, competent residents and the families of incompetent residents in nursing homes were willing to complete ADs. With the aid of trained facilitators, even patients with impaired cognitive function can understand and complete LMD directives.

Studies that measured knowledge and comprehension

Three studies [30, 40, 41] measured the changes in knowledge and comprehension of ADs.

Provision of written materials and videotape

Siegert et al. [30] compared the effects of an AD videotape to a health-related videotape shown to nursing home residents and measuring the residents' comprehension of AD concepts and preferences for resuscitation. All 36 participants in both groups received an educational booklet and an introductory explanation of ADs by a geriatric nurse practitioner.

There were no significant differences between the two groups in age, race, marital status, level of education, mental status score, health status, pain experience, or presence of depression, and reading comprehension. The study did not find any differences in terms of change in comprehension of AD concepts or preference for resuscitation between the intervention and control groups.

The authors offered the following observations to explain the lack of significant differences between the two groups:

1) overall, baseline comprehension of AD concepts among the residents was poor;
2) advanced age and lower educational levels were negatively associated with the level of understanding of CPR and living wills; or
3) the vocabulary, style, or pace of the information presented in the AD educational videotape may not have been appropriate.

The authors suggested that a revised videotape may need to tailor the information to the audience's cultural and educational background. An interactive videotape may also be a more engaging format to convey complex information in an individualized manner.

Yamada et al. [40] assessed the effects of educational handouts about ADs on the knowledge of and attitudes toward ADs among Veterans. The control group received a handout that only described ADs but did not specifically address CPR or the outcomes of CPR. The intervention group received the same handout, as well as another about CPR and its outcomes, and viewed a 10-minute videotape about ADs. Knowledge about what an AD was improved in both groups, but more significantly in the intervention group. There were no post-intervention differences between the two groups in their preferences for or activities regarding advance care planning. The difference between the two groups lessened or disappeared after two to four weeks. Only a few participants in either group actually discussed ADs with their physicians.

Physician-initiated discussion

Moore et al. [41] examined the effects of physician-initiated discussions about ADs on elderly outpatients' understanding of ADs, CPR, and ANH. One hundred patients from a family practice center were randomly assigned to either the AD discussion group (n = 85) or the general health promotion (HP) discussion group (n = 15) (the reason for the unequal number in the two groups is that multiple regression analysis planned for the data from the AD discussion required greater number of patients in the AD discussion group than in the HP discussion group).

There were three significant baseline differences between the two groups. Patients in the intervention group had more visits to their physicians, higher levels of depressive symptoms, and more strongly believed that their physician understood their life support wishes compared with patients in the control group. The study demonstrated no significant differences in performance level between the two groups on overall comprehension or on any subtopic. Both groups had a good basic knowledge about ADs, CPR, and ANH. The short, prepared discussions with the physicians did not improve patients' comprehension. The authors noted that older patients had less knowledge. Patients with less education and those whose physicians spent less time with them scored lower.

Summary

One systematic review and ten RCTs were located to examine the effects of various interventions on increasing discussion and completion of ADs or on improving knowledge and comprehension about ADs. This review updates the previous systematic review by Hanson et al. [12] but also includes studies that measured changes in knowledge and comprehension. Tables 1 and 2 summarize the important aspects from each of the primary studies to illustrate the difference among the studies.

The types and intensity of interventions assessed in the studies varied in the following ways:

- provision of written materials about ADs only [9];
- provision of written materials plus an educational videotape [30, 37, 40];
- provision of written materials plus interactive seminar [31];
- education session plus telephone reminder [28];
- physician-initiated brief discussion [39, 41] or computer-generated reminders for physician's discussion [38];
- comprehensive nurse-initiated AD educational program [15].

The types of ADs used in the studies varied. One Canadian study used LMD directive, a combination of instructional and proxy directives [15]. Most studies used separate forms for ADs containing different components such as living will, DPAHC, CPR directive, and organ donation card [9, 30, 31, 37-39]. The type of ADs was not specified in three studies [28, 40, 41].

Table 1: Summary of RCTs that measured AD completion

Study	Intervention/ type of AD	Setting/delivery personnel	Rate of AD completion
Rubin et al. [9]	Mailed written materials only/ DPAHC	HMO/not applicable	Baseline: 4.7% (EG) vs. 4.2% (CG) Post-intervention: 23.2% (EG) vs. 4.6% (CG) (p<.001)
Brown et al. [37]	Mailed written materials and videotape /living will, DPAHC	HMO/not applicable	Baseline: 18.9% (EG) vs. 21.2% (CG) Post-intervention: 32.6% (EG) vs. 35% (CG) (nss)
Landry et al. [31]	Handout of written materials and interactive seminar /living will, DPAHC, organ donation card	Outpatient clinic/physician & research assistant	Baseline: 0% Post-intervention: living wills: 38% (EG) vs. 24% (CG) (p<.05); DPAHCs: 37% (EG) vs. 24% (CG) (p<.05); Organ donation cards: 28% (EG) vs. 17% (CG) (nss)
Hamel et al. [28]	Education session and telephone reminder/not specified	Senior centre/researcher	Baseline: 0% Post-intervention: 32% (EG) vs. 18.9% (CG) (nss)
Dexter et al. [38]	Computer-generated reminders for physician-initiated discussion/ instructional directive, proxy directive	Outpatient clinic/physician	Baseline: 0% Post-intervention: 15% (Instruction/proxy AD reminder) vs. 4% (CG) (p<.001)
Grimaldo et al. [39]	Anesthesiologist-initiated discussion/ DPAHC	Preoperative evaluation clinic /anesthesiologist	Baseline: 11% (EG) vs. 9% (CG) Post-intervention: 27% (EG) vs. 11% (CG) (p=.004)
Molloy et al. [15]	Comprehensive education program/LMD, DNR, living will, power of attorney	Nursing home /nurse	Baseline: <25 % (% in each group not given) Post-intervention: 70% (EG) vs. 57% (CG)

CG: control group; DNR: do not resuscitation; DPAHC: durable power of attorney for health care; EG: experimental group; HMO: health maintenance organization; LMD: Let Me Decide; nss: not statistically significant; vs.: versus

Table 2: Summary of RCTs that measured knowledge/comprehension of ADs

Study	Intervention/ type of concepts	Setting/delivery personnel	Knowledge/comprehension
Siegert et al. [30]	Handout of written materials plus videotape /living will, CPR	Nursing home care unit/geriatric nurse practitioner	Comprehension: improved in all participants over time ($p<.001$) No significant difference between EG and CG
Yamada et al. [40]	Handout of written materials plus videotape/ADs, CPR	Outpatient clinic/physician	Knowledge: improved in both groups but more significant in EG ($p\leq.05$)
Moore et al. [41]	Physician-initiated discussion/ADs, CPR, ANH	Family practice center/ physicians	Comprehension: no significant difference between EG and CG

ADs: advance directives; ANH: artificial nutrition and hydration; CG: control group; CPR: cardiopulmonary resuscitation; EG: experimental group

The sample size, setting, and length of follow-up also varied across the studies (see Appendix B). The total number of participants in these studies ranged from 36 to 1,292. Although the majority of studies were conducted in outpatient settings, some participants were regular visitors at physician office, while others were recently discharged from an acute care hospital or attending a pre-operative evaluation clinic. In the studies in which changes of comprehension and knowledge about ADs were the outcome measures, the length of follow-up ranged from immediately after the intervention to 2 to 4 weeks later. In the studies where initiation of discussion about ADs and completion rates of ADs were measured, the period of follow-up was usually longer ranging from one month to 18 months. Who completed the ADs also varied. In the Molloy et al. study [15] the completion rate included ADs that were completed by competent residents as well as by family members of incompetent residents, while in most studies ADs were completed only by competent residents/patients. The competency assessment varied among the studies with some using a standardized approach and others using clinical judgment. The health state of the participants also differed among the studies as well as their mean age, which ranged from 62 to 81 years.

Taking all these variables into account and how these variables affect the results the following summaries the findings from the studies that measured effectiveness by comparing completion rates.

Results from these studies suggested that provision of written educational materials about ADs alone or in combination with videotape, and physician-initiated discussions with patients all yielded similar AD completion rates (around 15%); education plus telephone reminder increased the completion rate (32%), provision of written materials in addition to an interactive seminar significantly increased the AD completion rates

(38%); and a comprehensive and time consuming education program increased AD completion rates by at least 45% but these results need to be interpreted with caution.

The results from studies using change in knowledge or comprehension to measure the effectiveness of the interventions were mixed. Since this outcome measure is an intermediary outcome it is not as useful as measuring changes in completion rates.

ALBERTA EXPERIENCE

Promotion of the use of PDs

Personal directive experts at the Office of the Public Guardian in Alberta Seniors Ministry were contacted for information regarding the promotion, implementation, and impact of the Personal Directive Act in Alberta.

The Office of the Public Guardian has played a major role in promoting the use of PDs. Specialists at the office provide information and presentations about PDs to different community groups and individuals, such as health care professionals, financial planners, club members, senior groups, places of worship, societies/associations, and college students. The primary goal of these efforts is to raise public awareness of their right to complete a PD and the benefits of doing so. No attempts as of yet have been made to measure the completion rate after presenting the information.

There is currently no registry for completed PDs. No statistical data are available on how many Albertans have made an AD or PD. The Alberta Government does not provide any standardized directive forms for Albertans because the intent of the legislation is to empower the individual by focusing on their unique wishes, beliefs, and values as opposed to following a standardized form. Some organizations have prepared a PD form for ease of access by the interested public. The *Choosing Now for the Future* booklets are available upon request from the Office of the Public Guardian, where example forms are provided as a guide.

The Personal Directive Act does not require physicians or nurses to ask patients about whether they have a directive. No data are available for the current status of using ADs in long-term care facilities and there is no universal policy for using ADs.

Provincial survey

In 2000, the Education Resource Centre for Continuing Care Centre in Calgary conducted a provincial survey on the use of PDs at acute care, continuing care, and community care settings (personal communication, Cheri Komar, April, 2001). The survey consisted of 12 questions and 43 responses were received in total, with no response from four out of the 17 health regions.

The survey showed that the majority of the respondents had a policy regarding PDs. The continuing care sector most frequently asked admitted clients if they had a PD. Most of the care settings asked for a copy of the PD so it could be placed on the client's medical chart. Most of the respondents indicated that they had designated PD contacts or specialists to provide information for clients who did not have a PD but wanted more information. Most of the respondents indicated that they used the *Choosing Now for the Future* booklets on a routine basis when providing information to clients.

Implementation of LMD Personal Directive Program

In 2002, the Capital Health Authority completed an evaluation study of the LMD Personal Directive Program. The objectives of the study were to identify enablers or barriers to implementation, measure the effectiveness of the education program and measure program outcomes. The study was funded by the Alberta Medical Association's Medical Services Business Innovation Fund and was conducted in four continuing care centres in the Edmonton area. New admissions to these care centres or their outpatient programs over an eight-month period were offered the opportunity to participate (see Appendix C for study details).

The LMD program was chosen because it was viewed as a comprehensive program with educational materials available to support its delivery. As the LMD Program originates from Ontario, alterations to the original directive tools were required to ensure consistency with the Personal Directive Act of Alberta and its corresponding terminology. The directive document itself is referred to as a ***"personal directive"*** in Alberta as its contents may include health and personal care items as well as other items such as living arrangements, participation in social, educational and employment activities, legal matters, and service provider stipulations. An individual must be eighteen years of age or older to complete a PD. The term ***"agent"*** is used for the person(s) designated in a PD to make personal decisions on behalf of the individual mentioned in the directive.

Collaboration with Dr. W. Molloy resulted in an Alberta version of the *"Health and Personal Care Directive"* form and a *"Next of Kin Expression of Wishes for Health Care Decisions for the Incompetent Person"* form. The Health and Personal Care directive form is a legal document that must be followed by health care providers; the Next of Kin form is not a legally binding agreement but does allow family members to express their wishes in a written format.

During the study period, 146 clients were admitted to the participating continuing care centres/programs; 64 referrals were made to participate in the study. Once the LMD Program was reviewed with the clients and/or their families, 46 clients consented to participate in the study. Twenty-nine clients/family members completed either a PD form or a next of kin form within the study period.

Through this study, it was found that the age and condition of clients entering continuing care centres/programs prohibits many persons from completing the directive forms themselves. Of the persons who completed a form, only 55 percent were deemed competent to complete their own personal directive. The *"Screening*

Instrument to Assess Understanding to Complete an Advance Directive" tool was found to be a very valuable objective means for measuring client competency. Although some health care facilitators found it to be somewhat lengthy to administer, the outcome outweighed the time expended.

Due to the resources required, the Capital Health Authority has not developed a regional directive to adopt the LMD program at this time.

DISCUSSION

Modes of delivery of directives

Increase in AD completion

The effectiveness of interventions to deliver AD programs can be measured by the completion rate of ADs, which was the main outcome measurement in seven RCTs [9, 15, 28, 31, 37-39]. The completion rates varied considerably across these studies. Among most studies in which ADs were completed by competent individuals, increased AD completion rates ranged from 3% by a computer-generated proxy directive reminder [38] to 38% by handout of written materials and interactive seminar [31]. The study by Molloy et al. [15] involved both elderly and their families and the completion rate increased at least 45%.

Limited research evidence indicated that the mailing of written materials about ADs alone could increase completion rates by 18% [9]. Compared to the mailing of written materials alone, the addition of educational videotapes did not increase completion rate [37], while the addition of an interactive seminar significantly increased the AD completion rate by 38% [31]. Education session plus telephone reminder did not increase AD completion rate when compared to education session alone [28]. Physicians' discussion with outpatients increased AD completion rates by 15% [38] and 16% [39]. The most comprehensive and complex education program, LMD program, increased AD completion rate by at least 45% [15]. However, some aspects need to be taken into consideration when interpreting these results.

The study by Molloy et al. [15] was conducted in a controlled setting with the longest period of follow-up (18 months). In this multi-center study 49% of the competent residents and 78% of the families of incompetent residents completed ADs. The target population of this study was quite different from that of other studies, in which all ADs were completed by the elders themselves.

Improvement of knowledge and comprehension about ADs

Three RCTs [30, 40, 41] examined the impact of various interventions on a patient's comprehension and knowledge of ADs, CPR, and/or treatment preferences. The results from these studies were mixed. One study [40] showed that providing written materials on CPR and an educational videotape significantly improved patients' knowledge of CPR compared to only providing written materials about ADs. Another study [30] demonstrated that providing written materials plus videotape on ADs did not significantly affect patients' comprehension of AD-related concepts and treatment preferences compared to proving written material and a health related videotape.

Physicians' discussions based on a prepared script consisting of AD issues did not significantly improve patients' comprehension [41].

Professionals who deliver AD programs

Personnel involved in the delivery of AD programs in these studies included physicians [31, 38-41], nurses [15, 30], and researchers [28, 31]. Delivery personnel were not mentioned in the studies in which the interventions were a mail out of the educational materials and/or viewing an educational videotape [9, 37]. No study was designed to compare the results of an intervention delivered by different professionals, e.g., physicians versus nurses versus social worker. It seems difficult to determine who would be the best-qualified professionals to deliver AD programs without considering the modes for delivery, the complexity of the ADs, settings, and target populations.

In Molloy's study [15], for example, a comprehensive and complex document, the LMD, was delivered by registered nurses who were trained to provide clear explanations and answer residents' questions. Systematic implementation of the LMD directive in the intervention nursing homes, where many residents had impaired cognitive function, required a commitment of 100% of a nurse's time (standard work shift) over 6 to 8 months. Under these circumstances, registered nurses would be considered to be the best-qualified professionals to deliver the AD program.

On the other hand, if the AD program is targeted to outpatients, physicians may be thought to be the most appropriate. In general, outpatients expect their physicians to initiate discussions about directives. However, individual physician's interest, expertise, and time for such matters vary greatly [42]. The mixed results from several RCTs included in this report demonstrated the need for multidimensional interventions designed to enhance physicians' engagement and advocacy, and patient-physician communication.

Potential barriers

Time and resource issue

The complexity of the intervention and the type of ADs dictate the time and resources required. Personalized educational processes may be very effective in increasing AD completion rate. However, this type of educational method would be time consuming, labor intensive, and require a substantial amount of time and expertise.

Instructional directives are more complex than proxy directives and thus require a certain expertise for those charged with the responsibility to deliver the directive and also a greater time commitment for everyone involved.

Physicians' involvement

Although some evidence showed that patients would like physicians to initiate discussion on ADs, physicians' concerns about eliminating patients' hope for recovery, physicians' discomfort with the topic, and time constraints have been demonstrated to be significant barriers to discussion [10, 43]. For example, the study by Moore et al. [41] suggested that patients would have greater AD-related knowledge if physicians spent more time discussing ADs with patients.

Impaired cognitive capacity in the elderly

The evaluation of a person's mental capacity to complete an AD is complex [36]. Decision-specific capacity is recognized as the ability to understand pertinent information and to reason and deliberate about choices particularly to a specific decision [29]. The MMSE is the most commonly used measurement tool for assessing cognitive function of individuals in clinical settings [44]. Scores on an MMSE can be affected by English language skills, level of intelligence, and formal education level [44]. Molloy et al. [45] developed a standardized version of this test with explicit detailed guidelines for its administration and scoring. Research indicated that SMMSE is more reliable than the traditional MMSE [45] and accurately differentiated persons who can learn and ultimately complete ADs from persons who cannot [46].

However, there is a lack of consensus about how best to determine the required mental capacity of the person in order for them to complete an AD, as well as who should make the cognitive assessment [46]. Ideally, a simple, quantitative, accurate, and reproducible test should be used to determine mental capacity.

One of the challenges to deliver AD programs to the elderly is that this special subpopulation's cognitive capacity might already be impaired, particularly for those admitted to long-term care facilities, such as nursing homes. It is estimated that more than 4 million American adults currently have severe dementia and, among nursing home residents, a high prevalence of serious psychiatric disorders exist [13]. In Molloy's study [15], more than half of the participants were incompetent. Valid ADs may only be completed by individuals who currently possess sufficient rational capacity to understand and appreciate their viable choices and the personal consequences of those choices [13] while still residing in the community.

A growing body of literature supports the concept of *"decision-specific capacity"*, whereby persons with impaired, fluctuating, or questionable cognitive status may have the capacity to make some but not all health care decisions [21, 47]. The capacity necessary to execute an AD that addresses end-of-life treatments and decision making is thought to differ from the capacity needed to give informed consent for treatment. Even among different forms of ADs, the decisional complexity varies. Decision complexity relevant to a living will, for which a person must agree to or reject specific treatments, is greater than that needed for a DPAHC, in which the person is appointing someone to make treatment decisions for them. Hence, the standard for determining capacity can be simpler and less stringent in executing a DPAHC than would be required for a living will [47].

Ethnic origin, culture, and education

Most of the studies presented in this report excluded non-English-speaking seniors. The generalizability of findings to this population is of question. Research evidence from some studies suggests that persons who were non-Caucasian, and part of a minority race were less likely to have considered discussing and/or completing an AD [9], which may be associated with their own cultural values. The European American value of patient autonomy dictates that the individual patient ultimately makes all the decisions that influence his/her health. In many non-European American cultures, however, this responsibility lies with the family and community members [34].

Seniors with a higher level of education and socioeconomic status are more likely to complete ADs. Seniors with higher levels of education gained greater AD-related knowledge [41]. There seems to be a need to tailor AD delivery strategies to reflect and address these differences.

CONCLUSION

Advance directives have been endorsed widely as a means for the elderly to guide care before a possible future period of decision incapacity. Limited evidence indicates that the optimal methods to increase discussions with older persons about end-of-life health care issues and the completion of written directives remain unclear. Some promising trends in relation to the completion of ADs were observed when several strategies were combined:

Provision of written educational materials about ADs alone or in combination with videotape, and physician-initiated discussions with patients increased AD completion rates by around 15%.

Provision of written materials in addition to an interactive seminar significantly increased AD completion rates (38%) compared to provision of written materials alone.

Telephone reminder following an education session did not significantly increased AD completion rate compared to education session alone.

The results from a comprehensive and time intensive education program, which increased AD completion rate by at least 45%, suggest that the most effective methods are considerably more resource intensive, and therefore more costly. This program is also more demanding on the families because ADs were completed by both competent persons and family members of incompetent persons.

The best-qualified professionals to deliver AD program may be determined by the methods used for delivery, the complexity of the ADs, settings, and target populations.

There are many different formats of ADs currently available in Canada as there is no federal law on advance health care planning. Several provinces including Alberta have their own legislation.

Evaluation of cognitive capacity is a challenge. The MMSE was the most commonly used tool. Further research is required to identify a valid and reliable tool to access decision specific capacity.

The Personal Directive Act in Alberta does not require health care professionals to enquire about personal directions nor is there a provincial policy. Hence the regional health authorities may choose to implement customized programs. Capital Health Authority's experience suggests that implementing a regional directive program that is well established in one province such as Ontario's LMD personal directives may be a challenge due to the differences in the provincial legislations.

The 'Screening instrument to assess understanding to complete an advance directive' tool was found useful and due to time requirement the most appropriate facilitator may be a social worker or chaplain.

APPENDICES

APPENDIX A: METHODOLOGY

Search strategy

The literature search was conducted by the AHFMR Research Librarian between March 15 and March 19, 2004. Major electronic databases used include: Cochrane Library, NHS Centre for Reviews and Dissemination (CRD Databases: NHSEED, HTA, DARE), PubMed, EMBASE, CINAHL, Dissertation Abstracts, Web of Science. In addition, relevant library collections, web sites of clinical trials, practice guidelines, regulatory agencies, evidence-based resources and other HTA related agency resources (AETMIS, CCOHTA, ECRI) were searched. Internet search engines were also used to locate grey literature. Medical Subject Headings (MeSH) related to the topic are: Advance directives; Living wills, Advance care planning. Key terms include: personal directive(s); advance medical directive(s).

Limits: Searches were limited to English language, publication dates: 1993 to 2004, and the population aged of 55 years or older, where such function is available.

Database	Platform	Edition	Search Terms
CORE DATABASES			
Cochrane Library (UK): Database of Systematic Reviews; Central Register of Controlled Trials; Methodology Register	Issue 1, 2004 Licensed Web Resource	March 18, 2004	((advance next directive*) or (personal next directive*) or (living next will*))
CRD (UK): Health Technology Assessment Database NHS Economic Evaluation Database Database of Reviews of Effects	Licensed Web Resource http://nhscrd.york.ac.uk/welcome.htm	March 15, 2004	advance directive OR living will OR personal directive

Database	Platform	Edition	Search Terms
CORE DATABASES (cont'd)			
PubMed National Library of Medicine (MEDLINE, Pre-MEDLINE, HealthSTAR)	http://www.pubmed.gov	March 17, 2004	**Search 1:** living wills OR living will OR advance directive OR advance directives OR personal directive OR personal directives OR advance care planning Limit: Middle Aged + Aged: 45+ years, Limit: Randomized Controlled Trial OR Review Limit: Practice Guideline (no age limit) Limit: Meta-analysis (no age limit) **Search 2:** (living wills OR living will OR advance directive OR advance directives OR personal directive OR personal directives OR advance care planning) AND systematic[sb]
ECRI	www.ecri.org	March 15, 2004	Advance directive or advance directives
EMBASE	Licensed Resource Ovid	March 18, 2004	1 exp Living Will/ 2 "advance directives".mp. 3 "personal directive".mp. 4 "advance directive".mp. 5 "personal directives".mp. 6 "advance medical directive".mp. 7 "advance medical directives".mp. 8 or/1-7 9 "systematic$ review$".mp. 10 "critical$ apprais$".mp. 11 Meta Analysis/ 12 randomi$.mp. 13 9 or 10 or 11 or 12 14 13 and 8
ISI: Web of Science Science and Social Sciences Citation Index	Licensed Web Resource ISI Thompson	March 18, 2004	(((advance directive*) OR (living will*) OR (personal directive*) OR (advance medical directive*) OR (personal medical directive*)) AND ((systematic* review*) OR (critical* apprais*) OR (meta-analys*) OR (metaanalys*) OR (metanalys*) OR randomi*)) Timespan=1993-2004

Database	Platform	Edition	Search Terms
LIBRARY CATALOGUES			
NEOS (Central Alberta Library Consortium Catalogue)	http://www.neoslibraries.ca/	March 18, 2004	((advance directive$) OR (personal directive$)) AND (systemat$ OR critical$ OR metaanalysis OR meta-analysis OR randomi*) keyword search
AMICUS (National Library of Canada Public Catalogue)	http://www.nlc-bnc.ca/amicus	March 18, 2004	((advance directive?) OR (personal directive?)) AND (systemat? OR critical? OR metaanalysis OR meta-analysis OR randomi?)
CANADIAN RESOURCES			
Canadian Theses Portal National Library of Canada	http://www.nlc-bnc.ca/thesescanada	March 18, 2004	"advance" AND "directives"
CABOT	http://cahspr.ca/cabot/	March 18, 2004	**NOTE: this resource is not available at the moment**
AETMIS	http://www.aetmis.gouv.qc.ca	March 15, 2004	Advance directive = 0 hit
CCOHTA	www.ccohta.ca	March 15, 2004	Directive or directives = 0 hit
Health Quality Council of Saskatchewan	http://www.hqc.sk.ca/	March 15, 2004	Advance directive or advance directives =o hit
ICES Institute for Clinical and Evaluative Sciences	http://www.ices.on.ca/	March 15, 2004	Advance directive or advance directives or personal directive = 0 hit
EVIDENCE BASED RESOURCES			
ACP Journal Club	Ovid	March 18, 2004	1"advance directive".mp. 2"advance directives".mp. 3"advance medical directive".mp. 4"advance medical directives".mp. 5"personal directive".mp. 6"personal directives".mp. 7"living will".mp. 8 living wills.mp. OR/1-8
Clinical Evidence	http://www.clinicalevidence.com	March 15, 2004	Advance directive or advance directives = 0 hit

Database	Platform	Edition	Search Terms
CLINICAL PRACTICE GUIDELINES			
AMA Guidelines (Alberta Medical Assoc.)	http://albertadoctors.org	March 15, 2004	Browse the available list 0 relevant
CMA Clinical Practice Guidelines Database (Canadian Medical Assoc.)	http://mdm.ca/cpgsnew/cpgs/index.asp	March 16, 2004	Advance directive or advance directives
National Guideline Clearinghouse	www.ngc.gov	March 15, 2004	personal directive or advance directive
CLINICAL TRIALS			
ClinicalTrials.gov (US)	http://clinicaltrials.gov	March 15, 2004	Living will or living wills or advance directive or advance directives or personal directive or personal directives = 0 hit
OTHER SUBJECT DATABASES			
CINAHL	Licensed Resource Ovid	March 16, 2004	1"advance directive".mp. 2"advance directives".mp. 3"advance medical directive".mp. 4"advance medical directives".mp. 5"personal directive".mp. 6"personal directives".mp. 7"living will".mp. 8 living wills.mp. 9 exp Advance Directives/ 10 or/1-9 11 limit 10 to ((middle age <45 to 64 years> or aged <65 to 79 years> or "aged <80 and over>") and systematic review OR practice guidelines) 12 randomi$.mp. 13 10 and (11 or 12)
Dissertations Abstracts UMI, US	http://www.lib.umi.com/dissertations	March 19, 2004	1 KEY((advance directive?)) 2 KEY((personal directive?)) 3 KEY((advance medical directive?)) 4 KEY((living will?)) 5 KEY((systematic? review?)) or KEY((critical? apprais?)) or KEY((random? control? trial?)) 6 KEY(meta-analy?) or KEY(metaanaly?) or KEY(metanaly?) 7 (#6 OR #5) and (#4 or #3 or #2 or #1) = 0 hit

Database	Platform	Edition	Search Terms
OTHER SUBJECT DATABASES (cont'd)			
PsycInfo	Licensed Resource Ovid	March 18,2004	1"advance directive".mp. 2"advance directives".mp. 3"advance medical directive".mp. 4"advance medical directives".mp. 5"personal directive".mp. 6"personal directives".mp. 7"living will".mp. 8 living wills.mp. 9 exp Advance Directives/ 10 or/1-9 limit 10 to (("aged <age 65 yrs and older>" or "very old <age 85 yrs and older>") and ("clinical trial" or "literature review/research review" or meta analysis))
NLM Gateway (NLM US) (meeting abstracts, consumer reports, clinical trials)	http://gateway.nlm.nih.gov/gw/Cmd	March 19, 2004	(living wills OR living will OR advance directive OR advance directives OR personal directive OR personal directives OR advance care planning) AND ((systematic review) OR (critical appraisal) OR (randomized controlled trials) OR (randomized controlled trial))
REGULATORY AGENCIES/LICENSING AGENCIES/COVERAGE AGENCIES			
Alberta Health and Wellness	http://www.health.gov. ab.ca	March 19, 2004	Advance directive
NICE (UK)	http://www.nice.org.uk/	March 15, 2004	"advance directive" OR "advance directives" OR "living will" OR " living wills" OR "personal directive" OR "personal directives" =0 hit

Note: * is a truncation character that retrieves all possible suffix variations of the root word e.g. surg* retrieves surgery, surgical, surgeon, etc. In databases accessed via the Ovid platform the truncation character is $.

Study selection

Studies will be included if they meet all of the following criteria:

- Studies that provided detailed descriptions of an advance health care directive;
- Study design includes systematic reviews or RCTs that compared two or more delivery methods;
- Study population includes seniors aged 55 years or older, particularly long term care facility residents who have chronic or terminal illness;

- Studies that were conducted in non-acute health care settings, such as nursing homes, outpatient clinics, or senior centres
- Outcome measurements include AD-related knowledge and attitude, rates of AD completion/discussion or placement on medical records for the first time;
- Studies published from 1993 onwards in English.

Data extraction

Author, country, year of publication;

Study objective and design;

Number and age of participants;

Intervention and comparator;

Setting and delivery (including delivery personnel and previous training);

Outcome

Methodological quality appraisal

All studies included in this report were systematic reviews or RCTs. No formal appraisal of methodological quality of included RCTs was performed.

Local contact

The Capital Health Authority and the Chinook Health Region were contacted for information about their experience in the use of ADs within their regions.

APPENDIX B: EFFECTIVENESS OF AD DELIVERY PROGRAMS

Table 3: Evidence from RCTs that measured AD completion/discussion

Study	Participant	Intervention	Setting/delivery	Outcome	Conclusion
Provision of written materials only					
Rubin et al. 1994 [9] USA **Objective:** to investigate whether a simple educational intervention increased completion rates of DPAHC forms.	**Total number:** 1101 patients aged 65 years and older who were discharged from an acute care hospital. EG: n = 552 CG: n = 549 **Age:** mean 76 years **Exclusion:** patients 1) discharged from the hospital in less than 3 days, 2) did not speak English 3) did not have health insurance **Assessing competency:** not available	**Intervention:** mailed materials including an educational brochure describing the DPAHC, and a DPAHC form. **Comparator:** conventional care **Follow-up:** 5 months	**Setting:** health maintenance organization **Delivery personnel:** not applicable **Training:** not applicable	**Increased AD completion:** 18.5% in the EG vs. 0.4% in the CG ($p<.001$).	A simple educational intervention significantly increased the completion rates of DPAHC forms.
Provision of written material and videotape					
Brown et al. 1999 [37] USA **Objective:** to compare the effectiveness of two means, written materials only versus written materials and an educational videotape, for increasing the use of ADs.	**Total number:** 1247 seniors aged 75 years or older who used the Franklin Medical Office EG: n = 619 CG: n = 628 **Age:** mean 81 years **Exclusion:** patients 1) were withdrawn by their physicians because of blindness, illiteracy, or dementia 2) moved out of the area 3) whose medical record could not be located. **Assessing competency:** not available	**Intervention:** mailed written material + videotape (*Peace of Mind: Advance Directive* videotape) **Comparator:** mailed written material only **Follow-up:** 3 months	**Setting:** not-for-profit group-model health maintenance organization **Delivery personnel:** not applicable **Training:** not applicable	**Increased AD completion & placement of AD in the medical record:** 13.7% in the EG vs. 13.8% in the CG ($p=.952$)	Mailing of written materials substantially increased placement of an AD on the medical record, but the addition of AD videotape did not.

Table 3: Evidence from RCTs that measured AD completion/discussion (cont'd)

Study	Participant	Intervention	Setting/delivery	Outcome	Conclusion
Provision of written materials and interactive seminar					
Landry et al. 1997 [31] USA **Objective:** to examine whether a simple educational intervention would increase completion of ADs and discussions on end-of-life issues.	**Total number:** 187 outpatients EG: n = 95 CG: n = 92 **Age:** mean 62 years **Exclusion:** seniors who were unable to complete questionnaire due to language or cognitive barriers. **Assessing competency:** not available	**Intervention:** l hour interactive seminar + informational pamphlet and AD forms The seminar included 1) a 10-min didactic presentation; 2) a 15-min videotape; 3) a 30-min interactive discussion; 4) distribution and review recommended AD form (10 min). **Comparator:** mailed pamphlet and AD forms only **Follow-up:** 1 month	**Setting:** outpatient clinic of a teaching hospital **Delivery personnel:** physician and research assistant **Training:** research assistant was trained by the physician in two sessions to ensure consistency in the presentations.	**Increased AD completion:** 38% in the EG vs. 24% in CG (p = .04) Caucasian, married seniors were more likely to complete AD. **Discussion on advance planning:** 73% in the EG vs. 57% in the CG (p = .02)	Mailed information alone for medical outpatients can increase completion of AD. A simple educational seminar can further increase completion rates.
Education session and telephone reminder					
Hamel et al. 2002 [28] Canada **Objective:** 1) to determine whether an individualized intervention (a phone call that responded to questions about ADs and offered more information) would lead to increased discussion and completion of ADs in a sample of older adult community dwellers; 2) to identify some factors associated with discussing and completing ADs.	**Total number:** 74 seniors belonging to a senior centre EG: n = 37 CG: n = 37 **Age:** mean 72 years (range from 54 to 93 years) **Exclusion:** persons who 1) were younger than 50 years 2) were unable to read, write, and understand English 3) already had completed AD **Assessing competency:** not available	**Intervention:** education session + telephone reminder **Comparator:** educational session only **Follow-up:** 3 months	**Setting:** a senior centre that provides educational, recreational, health, and social opportunities to older adults **Delivery personnel:** researcher **Training:** not available	**Increased AD completion:** 32.4% in the EG vs. 18.9% in the CG (nss) **Discussion of ADs:** 75.7% in the EG vs. 59.5% in the CG (nss).	This study did not support the hypothesis that a cue to action such as a personalized intervention (phone call) would enhance completion and/or discussion of ADs. A probable explanation is that the cue to action was not intense enough to stimulate action.

Table 3: Evidence from RCTs that measured AD completion/discussion (cont'd)

Study	Participant	Intervention	Setting/delivery	Outcome	Conclusion
Physician initiated discussion					
Dexter et al. 1998 [38] USA **Objective:** to determine the effects of computer-generated reminders to physicians on the frequency of AD discussions between patients and their primary caregivers and completion of ADs.	**Total number:** 147 primary care physicians & 1009 patients 1) EG1(Instructional AD reminder): n = 30 physicians, 219 patients 2) EG2 (proxy AD reminder): n = 31 physicians, 260 patients 3) EG3 (instructional/proxy AD reminders): n = 37 physicians, 277 patients 4) CG (no reminder): n = 49 physicians, 253 patients **Age:** mean 65 years **Exclusion:** patients 1) from nursing homes and prisons 2) were deaf 3) did not speak English 4) cognitive dysfunction **Assessing competency:** Pfeiffer Mental Status Questionnaire	**Intervention:** computer-generated reminders that recommended discussion **Comparator:** no reminder **Follow-up:** 1 year	**Setting:** outpatient general medical practice affiliated with an urban public hospital **Delivery personnel:** physicians **Training:** presentation on the basic concepts of AD at grand rounds, face-to-face meeting	**Increased AD completion:** EG1: 7% EG2: 3% EG3: 15% vs. CG: 4% (p<.001) **Discussion about AD:** EG1: 14% EG2: 8% EG3: 24% vs. CG: 4% (p<.001).	Simple computer-generated reminders aimed at primary caregivers can increase the rates of discussion of AD and completion of AD forms among elderly outpatients with serious chronic conditions such as cardiac ischemia, heart failure, or chronic lung diseases.

Table 3: Evidence from RCTs that measured AD completion/discussion (cont'd)

Study	Participant	Intervention	Setting/delivery	Outcome	Conclusion
Physician-initiated discussion					
Grimaldo et al. 2001 [39] USA **Objective:** to evaluate the feasibility of a short (5 to 10 minutes) discussion designed to foster dialogue between patients and their proxies facilitated by anesthesiologists.	**Total number:** 200 patients aged 65 years or older who were scheduled for elective surgery EG: n = 100 CG: n = 100 **Age:** mean 72.8 years **Exclusion:** patients who did not speak or write English **Assessing competency:** Pfeiffer Mental Status Examination (patients who made more than 2 errors on the examination were excluded)	**Intervention:** received a 5 to 10-min information session about DPAHC with one of four anesthesiologists during pre-operative evaluations. **Comparator:** received standard pre-operative screening and counseling during their visit with one of the same four anesthesiologists. **Follow-up:** not clear	**Setting:** pre-operative evaluation clinic **Delivery personnel:** anesthesiologists **Training:** the anesthesiologists were given guidelines in the form of a one-page script. The main points and goals of the intervention were also discussed among the participating anesthesiologists before the initiation of the study.	**Increased AD completion:** 16% in the EG vs. 2% in the CG (p=.004). **Discussion about advance care planning:** 17% in the EG vs. 5% in the CG (p<.001).	The pre-operative intervention significantly increased discussions between patients and their proxies regarding ADs. The pre-operative evaluation offers an opportunity to increase patient communication regarding ADs with physicians who have limited relationships with the patients, yet have expertise and training in the intensive care unit.

Table 3: Evidence from RCTs that measured AD completion/discussion (cont'd)

Study	Participant	Intervention	Setting/delivery	Outcome	Conclusion
Comprehensive education program					
Molloy et al. 2000 [15] Canada **Objective:** to examine the effect of systematically implementing an AD in nursing homes on patient and family satisfaction with involvement in decision making and on health care costs.	**Total number:** 1292 residents from 6 Ontario nursing homes EG: n = 3 nursing homes (636 residents) CG: n = 3 matched nursing homes (656 residents) **Age:** mean 84 years **Exclusion:** not available **Assessing competency:** nurses' experience and the SMMSE	**Intervention:** comprehensive education program (nurse-initiated discussion) **Comparator:** conventional use of AD (did not offer any particular AD) **Follow-up:** 18 months	**Setting:** nursing home **Delivery personnel:** registered nurses **Training:** a 2-day workshop	**Increased AD completion:** *at least 45% in the EG (89% of the completed directives were LMD) vs. at least 32% in the CG (71% of the completed directives were DNR) (statistical significance was not reported). * Baseline AD completion rates were less than 25% in both groups but the actual numbers were not reported (the first author of this study was contacted for information on baseline completion rate, but no responses were obtained). 25% was taken as baseline AD completion rate which yielded the minimal increase of AD completion rate of 45% in the EG.	Systematic implementation of a program to increase use of AD reduces health care services utilization without affecting satisfaction or mortality.

AD: advance directive; CG: control group; CPR: cardiopulmonary resuscitation; DNR: do not resuscitation; DPAHC: durable power of attorney for health care; EG: experimental group; LMD: Let Me Decide; min: minutes; nss: not statistically significant; SMMSE: Standardized Mini-Mental State Examination

Table 4: Evidence from RCTs that measured knowledge/comprehension

Study	Participant	Intervention	Setting/delivery	Outcome	Conclusion
Provision of written materials plus videotape					
Siegert et al. 1996 [30] USA **Objective:** to examine the effects of an AD videotape program on patient comprehension of living wills and preferences for CPR.	**Total number:** 36 nursing home residents EG: n = 16 CG: n = 20 **Age:** mean 69 years **Exclusion:** residents 1) were acutely ill or had severe cognitive impairment 2) could not adequately paraphrase the introductory explanation of the study **Assessing competency:** MMSE	**Intervention**: received written material and counseling on AD + observed an AD videotape **Comparator:** received written material and counseling on AD + observed a health-related videotape **Follow-up:** 14 - 16 days	**Setting:** nursing home care unit **Delivery personnel:** geriatric nurse practitioner **Training:** not mentioned	**Change in comprehension:** mean comprehension scores for all participants improved over time (p<.001). No significant difference in the change of mean comprehension scores between the two groups. **Preference of resuscitation:** mean resuscitation preference scores were stable over time. No significant difference between the two groups	The AD videotape did not significantly affect resuscitation preferences or comprehension of selected AD concepts.
Yamada et al. 1999 [40] USA **Objective:** to assess the effects of a multimedia educational intervention about AD and CPR on the knowledge, attitude and activity toward AD and life-sustaining treatments.	**Total number:** 117 Veterans EG: n = 62 CG: n = 55 **Age:** mean 74 years **Exclusion:** patients who were unable to provide valid consent **Assessing competency:** investigator's judgment	**Intervention:** usual handouts (not specifically address CPR or the outcome of CPR) + handouts describing procedural aspects and outcomes of CPR + a videotape about AD. **Comparator:** usual handout about AD **Follow-up:** 2 - 4 weeks	**Setting:** general medical clinic of a university-affiliated Veterans Affairs Medical Center **Delivery personnel:** physician **Training:** not mentioned	**Improved knowledge about AD:** immediate after intervention: 59.1% in the EG vs. 25.1% in the CG ($p \le .05$) at 2-4 week follow-up: 44.6% in the EG vs. 12.6% in the CG ($p \le .05$)	The multimedia educational intervention improved short-term knowledge about AD and CPR for elderly male patients, but did not stimulate advance care planning.

Table 4: Evidence from RCTs that measured knowledge/comprehension (cont'd)

Study	Participant	Intervention	Setting/delivery	Outcome	Conclusion
Physician-initiated discussion					
Moore et al. 1994 [41] USA **Objective:** to determine whether elderly outpatients' understanding of AD, CPR, and artificial nutrition and hydration (ANH) was improved by a physician-initiated discussion.	**Total number:** 100 outpatients aged 65 years or older EG: n = 85 CG: n = 15 **Age:** mean 72 years **Exclusion:** patients 1) whose spouses participated in the study; 2) with charted diagnosis of dementia, depression, schizophrenia, severe communication disorder, or terminal illness. **Assessing competency:** Short Portable Mental Status Questionnaire for dementia	**Intervention:** physician's discussion based on a prepared script consisting of AD issues **Comparator:** physician's discussion based on a prepared script consisting of health promotion issues **Follow-up:** immediately following the physician-initiated discussion	**Setting:** family practice center **Delivery personnel:** physicians **Training:** all physicians received training in the conduct of study discussions to improve standardization.	**Comprehension of AD, CPR, & ANH information:** patients in both groups showed good basic understanding. No significant difference between the two groups on overall comprehension or on comprehension of AD, CPR, and ANH. Younger, better-educated patients and those who had longer unstructured discussion had greater AD-related knowledge.	The patients' comprehension was not improved by short, prepared discussions with physicians. The level of comprehension in both groups was quite good. This suggests that, even in the absence of explicit explanations by physicians, older adults have a reasonable working knowledge about AD, CPR, and ANH.

AD: advance directive; ANH: artificial nutrition and hydration; CG: control group; CPR: cardiopulmonary resuscitation; EG: experimental group; MMSE: Mini-Mental State Examination; vs.: versus

APPENDIX C: EVALUATION OF THE *LET ME DECIDE PERSONAL DIRECTIVE PROGRAM:* THE ALBERTA EXPERIENCE

A multitude of agency specific *"advance directive"* forms as well as a variety of personal directive forms within the continuing care sector had led to inefficiencies, ineffective care and problems with health care providers following directives. Consideration for a regional directive to encourage all care centres to adopt the same directive forms and implement a standardized education program for residents and families was the impetus for evaluating **'Let Me Decide'.** **'Let Me Decide'** was chosen because it was viewed as a comprehensive program with educational materials available to support its delivery. The inclusion of a tool to screen client competency prior to the completion of a directive was also deemed to be very beneficial.

As the **'Let Me Decide'** Program originates from Ontario, alterations to the original directive tools were required to ensure consistency with the *Personal Directive Act* of Alberta and its corresponding terminology. The directive document itself is referred to as a *"personal directive"* in Alberta as its contents may include health and personal care items as well as other items such as living arrangements, participation in social, educational and employment activities, legal matters, and service provider stipulations. An individual must be eighteen years of age or older to complete a personal directive. The term *"agent"* is used for the person(s) designated in a personal directive to make personal decisions on behalf of the maker.

In Ontario, the *Substitute Decisions Act* regulates the use of the directive. This legislation permits a person sixteen years of age or older to assign another person *"power of attorney for personal care"*. In Alberta, the term "power of attorney" refers to an individual who has responsibility for another's financial matters, thus it was felt that in order to avoid confusion when educating clients, it was essential that the terminology used matched Alberta legislation. Additionally, once a client has lost the competence to direct his or her own health care and a personal directive is not present, Alberta legislation does not permit the assignment of a substitute decision maker. Next of kin may make their wishes known, but the health care team is not legally bound to follow their directions.

Collaboration with Dr. W. Molloy resulted in an Alberta version of the "Health and Personal Care Directive" form and a "Next of Kin Expression of Wishes for Health Care Decisions for the Incompetent Person" form. The Health and Personal Care directive form is a legal document that must be followed by health care providers; the Next of Kin form is not a legally binding agreement but does allow family members to express their wishes in a written format.

During the study period, 146 clients were admitted to the four participating continuing care centres/programs; 64 referrals were made to participate in the study. Once the **'Let Me Decide'** Program was reviewed with the clients and/or their families, 46 subjects consented to partake in the study. Twenty-nine clients/family members completed either a personal directive form or a next of kin form within the eight month study period.

Through this study, it was found that the age and condition of clients entering continuing care centres/programs prohibits many individuals from completing the directive forms themselves. Of the subjects who completed a form, only 55 percent were deemed competent to complete their own personal directive. The *"Screening Instrument to Assess Understanding to Complete an Advance Directive"* tool was found to be a very valuable objective means for measuring this client competency. Although some health care facilitators found it to be somewhat lengthy to administer, the outcome outweighed the time-expended issue.

The client education process with **'Let Me Decide'** and the provision of assistance with completion of personal directives within this client population was found to be much more labor intensive for the health care facilitator involved as compared to existing means of obtaining such information. The average staff time taken to complete the education and a directive with a client/family in a care centre was 2.68 hours. The same process with a client in an outpatient program averaged 4.61 hours. The implementation process entailed the following:

- Meeting with the client and his/her family to discuss personal directives.
- Completing a Standardized Mini-Mental State Exam on the client.
- Discussing the 'Let Me Decide' Program and its directive forms, and viewing the video.
- Providing a time for personal reflection, further reading, etc.
- Completing the Screening Instrument to Assess Understanding to Complete an Advance Directive on the client to determine competency.
- Re-educating the client / family on areas of weakness as identified during the screening.
- Re-testing the client using the Screening Instrument to Assess Understanding to Complete an Advance Directive.
- Assisting the client/family with completion of the directive and next of kin forms.

The impact of the standardized education program with **'Let Me Decide'** was evident in the choices clients selected with respect to end-of-life care. In the event of an irreversible illness, only 8 percent of clients stated they would want intensive or surgical care, 91 percent chose basic or supplemental feeding and 96 percent stated no CPR.

Feedback on the **'Let Me Decide'** Program was very positive from clients, families and health care providers. Regarding the directive forms, 63 percent of subjects found the forms were easy to complete; 31 percent stated that they were somewhat confusing. This discrepancy may have depended on the time, assistance provided, and the explanations given by the health care facilitator at the care centre who provided assistance to the subjects in this process.

In order to ensure consistency in program delivery and successful implementation, the designation of one or two health care facilitators for a care centre/program is recommended. These individuals must have dedicated time to invest in the process of planning end-of-life care with clients and/or families in a non-threatening way. In this study, a social worker or chaplain was found to be the most appropriate facilitator for this program, as they could devote the necessary time to discussions with clients and their families. Where multiple registered nurses were assigned the responsibility for program implementation within a care centre, the number of completed directives was minimal, as these professionals could not complete the program components in addition to their existing responsibilities in a timely manner.

A sustainable commitment of human resources is essential if **'Let Me Decide'** program is to be effectively implemented in a clinical setting. Due to the resources required, Capital Health has not developed a regional directive to adopt **'Let Me Decide'** program at this time.

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